



Psychiatric co-morbidities and feasibility of an online psychiatric screening measure in children and adolescents with the Fontan circulation

Original Article

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Abstract

Background: Guidelines recommend screening for psychiatric co-morbidities in patients with congenital heart defects alongside cardiac outpatient follow-ups. These recommendations are not implemented in Denmark. This study aimed to investigate the psychiatric co-morbidities in children and adolescents with Fontan circulation in Denmark and to evaluate the feasibility of an online screening measure for psychiatric disorders. **Methods:** Children, adolescents, and their families answered the Development and Well-Being Assessment questionnaire and a questionnaire about received help online. Development and Well-Being Assessment ratings present psychiatric diagnoses in accordance with ICD-10 and DSM-5. Parent-reported received psychiatric help is also presented. Feasibility data are reported as participation rate (completed Development and Well-Being Assessments) and parental/adolescent acceptability from the feasibility questionnaire. **Results:** The participation rate was 27%. Of the participating children and adolescents, 53% (ICD-10)/59% (DSM-5) met full diagnostic criteria for at least one psychiatric diagnosis. Of these, 50% had not received any psychiatric or psychological help. Only 12% of participants had an a priori psychiatric diagnosis. **Conclusions:** We found that a large proportion of children and adolescents with Fontan circulation are underdiagnosed and undertreated for psychiatric disorders. The results from our study emphasise the need for psychiatric screening in this patient group. Development and Well-Being Assessment may be too comprehensive for online electronic screening in children and adolescents with CHD.

Introduction

Patients with CHD have an increased risk of neurocognitive difficulties,^{1–6} whereas the risk of psychiatric co-morbidities has been less investigated. Two recently published studies found that children and adolescents with especially complex CHD had an increased risk of neurodevelopmental disorders such as autism spectrum disorders and attention deficit hyperactivity disorders).^{7,8} In addition, the register-based study found an increased risk of anxiety disorders.⁸

Adults with CHD are at risk of being underdiagnosed and undertreated for psychiatric disorders.^{9,10} To limit this and to enhance the overall quality of life and life trajectory American Heart Association and Cardiac Neurodevelopmental Outcome Collaborative (CNOC) guidelines have recommended screening for both neurocognitive and psychiatric co-morbidities as parts of cardiac follow-ups.^{11,12} In Denmark, these follow-up programmes are not yet established.

Medical professionals in somatic settings may find it difficult to identify emotional and behavioural problems¹³ with one potential barrier being the limited consultation time.^{14,15} An online screening method for psychiatric disorders to be answered at home by parents and children could be a solution to the limited time available.

The Development and Well-Being Assessment (DAWBA) is a validated, multi-informant standardised diagnostic assessment. Online administration makes the Development and Well-Being Assessment useful as a potential screening tool for psychiatric disorders in the context of a time-limited outpatient appointment. The Development and Well-Being Assessment can be used to make tentative psychiatric diagnoses.^{16,17} It can be answered online by parents/adolescents and/or administered as an interview. The Development and Well-Being Assessment has been tested as a screening method for psychiatric disorders in different clinical populations as part of research studies. In these settings, participants have been recruited at clinical appointments, and Development and Well-Being Assessment has been found feasible both in terms of participation rate (around 50%) and parental acceptability.^{18,19}

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The Development and Well-Being Assessment has also been used in large community surveys, where participants were recruited through letters and administered as interviews by interviewers.^{20,21} The participation rate was 83% and 72%, respectively.

This study is the first part of the larger “Mind the Heart” project. “Mind the Heart” sets out to investigate the psychiatric comorbidities in children and adolescents with CHD in Denmark and a potential screening tool. We investigate the feasibility of providing Development and Well-Being Assessment as an online survey administered without an interviewer and outside of clinical care. Participants were recruited through email as many children and adolescents with simple CHD are not seen at regular hospital appointments.

We started with the group of patients with the most complex types of CHD, the Fontan circulation.

Aim

The first aim was to report on psychiatric co-morbidity in children and adolescents with the Fontan circulation in Denmark and the parent-reported psychiatric or psychological help received. The second aim was to investigate the feasibility of using Development and Well-Being Assessment as an online screening procedure (outside regular clinical care) for psychiatric morbidity in this patient group. Feasibility in this study measured as participation rate and parental acceptability investigated through a questionnaire.

Materials and methods

Study design

The study is designed as a national cross-sectional survey. The recruitment period was 6 months from March 2023 to September 2023.

Participants

All school-aged children and adolescents (5–17 years) with the Fontan circulation living in Denmark were eligible for participation. The Danish Health Data Authority identified the study population as individuals with CHD diagnoses (DQ20*, DQ226, and DQ234) and Fontan surgery procedure codes) registered at the National Patient Register. Heart-transplanted children and adolescents were excluded.

Study procedure

Study flow diagram (Figure 1).

Informed consent

Eligible participants were sent study information before providing written informed consent. Study information and informed consent forms were through REDCap (<https://redcap.regionh.dk/>), and a national secure email system (Eboks). Those not responding electronically were sent a letter containing study information, consent forms, and a pre-paid return envelope to heighten the participation rate during the inclusion period.

Informed consent was obtained from all parental authority holders for children and adolescents below 15 years of age, as well as from adolescents 15 years of age and older.

Overview of study components

Participants were asked to respond to an online survey containing a background, a current help questionnaire, the Development and Well-Being Assessment, and a feasibility questionnaire. Children and adolescents 11 years or older were also asked to complete the Development and Well-Being Assessment.

Several initiatives were taken to ensure participation: “Advertising” for the study in relevant Facebook groups, through flyers at relevant departments throughout Denmark, in the national magazine published by the Danish Heart Association, and at the yearly meeting for families with a child/adolescent with CHD, and finally using both mail and telephone reminders throughout the study (Figure 1).

Background questionnaire

The background questionnaire in the study was made in collaboration with experts in CHD and child and adolescent psychiatry (questions in Danish can be provided upon request). The background questionnaire included questions about the child’s other somatic disorders, medical use, school, parental income, and parental psychiatric history.

To compare the participants with the non-participants we used background characteristics of a sub-group of the participants from the study “DAN-FONTAN 2”.^{22–24} “DAN-FONTAN 2” included the entire Danish cohort of children, adolescents, and adults with the Fontan circulation.

Current help questionnaire

The questionnaire on current help was based on previous studies^{25,26} and modified to fit this study set-up (questions in Danish can be provided upon request).

Both the background questionnaire and the current help questionnaire were pilot-tested on four families with children and adolescents with CHD before study start.

DAWBA

The Development and Well-Being Assessment is a validated psychiatric diagnostic assessment (<https://dawba.info/a0.html>). For any psychiatric diagnosis, the minimum specificity is 89% in a community sample (assuming none of the participants from the community sample had a psychiatric diagnosis), and the minimum sensitivity is 92% in a clinical sample (assuming all of the participants in the clinical sample had a psychiatric diagnosis).¹⁶

Development and Well-Being Assessment has shown high interrater reliability across clinical and community samples, with a Kappa coefficient of 0.83 (95% CI 0.68–0.97) for any diagnosis in clinical settings¹⁷ and 0.86 (SE 0.004) for any diagnosis in community settings.²⁰ Furthermore, Development and Well-Being Assessment exhibits good diagnostic agreement with clinical interview diagnoses with a Kappa coefficient of 0.64 and 0.30.^{16,17} Development and Well-Being Assessment has been translated into many languages including Danish. The Development and Well-Being Assessment was securely distributed online via a secure website (<https://dawba.dk/>). Data are saved in a secure and GDPR-compliant database.

The Development and Well-Being Assessment consists of both closed and open-ended questions such as “Does your child have problems with hyperactivity” (closed) (derived from the diagnostic criteria in ICD-10 and DSM-5) and “Please describe the symptoms

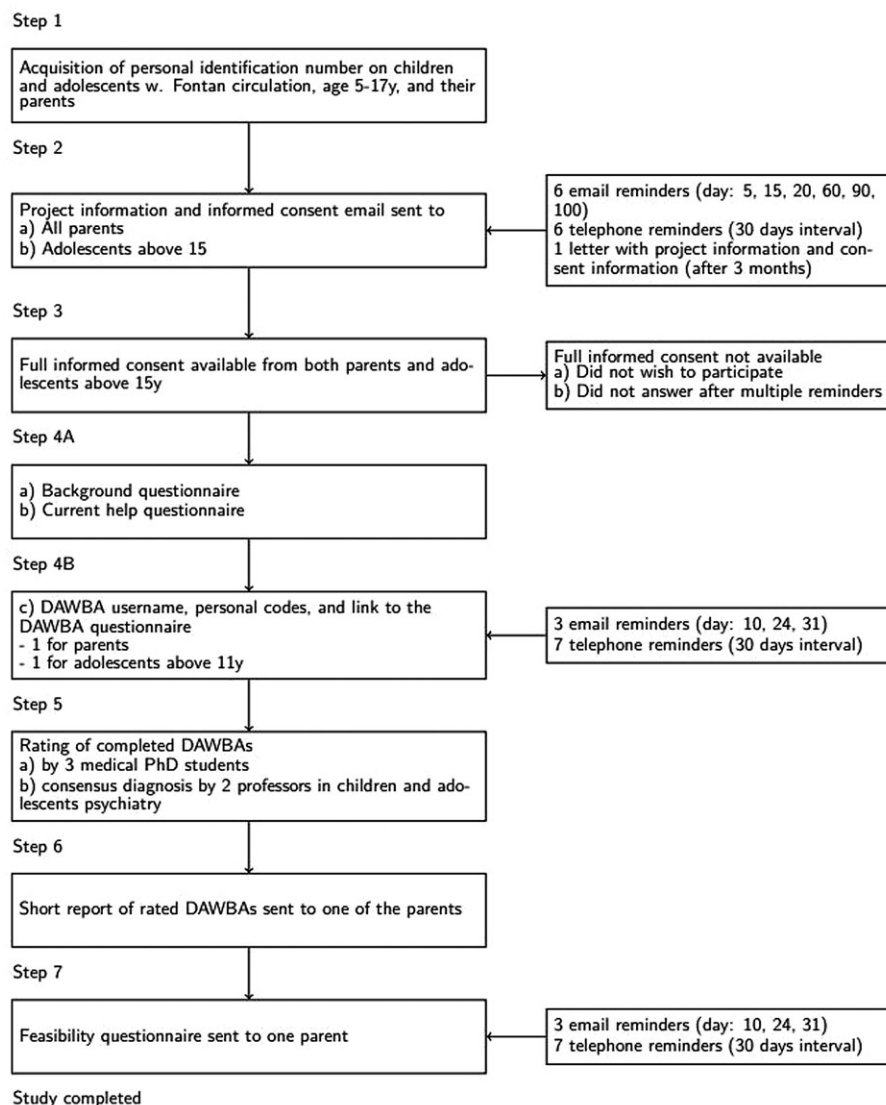


Figure 1. Study procedure.

in more detail” (open). Questions about the impairment of daily functioning due to psychiatric symptoms (impact questions) are a crucial aspect of the Development and Well-Being Assessment, as a psychiatric diagnosis is only made if the symptoms also disrupt the child’s daily activities.

The diagnoses that can be assessed by Development and Well-Being Assessment are seen in Supplementary Table S1.

The Development and Well-Being Assessment generates computer-based diagnoses based on responses of informants to the closed questions. Trained clinical raters subsequently review both closed, open-ended, and impact questions to assign clinical diagnoses. The questionnaire can be distributed to 1–2 parents, to children and adolescents age 11 years and older, and in a short version to teachers.

Development and Well-Being Assessment (in different versions) is used on children and adolescents between 2 years and 18 years of age. We did not use the teacher report.

Ratings

After completion of the Development and Well-Being Assessment, three trained independent junior medical doctors

(LT, JLH, and SLJ) rated the Development and Well-Being Assessments and made tentative consensus diagnoses of either a “sure”, “unsure”, or “no” diagnosis according to both ICD-10 and DSM-5. Professors in child and adolescent psychiatry (CUR/MBL) subsequently verified all tentative consensus diagnoses. The diagnoses generated by the rating were used for research purposes only.

Report

A short report based on the answers provided by the parent(s) (and adolescents) was written by two junior doctors (JLH/SLJ). The short report described the child’s strengths and difficulties in free writing and was sent to the parents and adolescents above 15 years of age. No specific diagnosis was listed. The short report also included a link to a webpage (Mind the Heart: http://www.rigshospitalet.dk/afdelinger-og-klinikker/tvaergaende_enheder/enheden-for-medfoedte-hjertesygdomme/mind-the-heart/Sider/default.aspx) where the families could look for further help and guidance if needed. All reports were approved by professors in child and adolescent psychiatry (CUR/MBL).

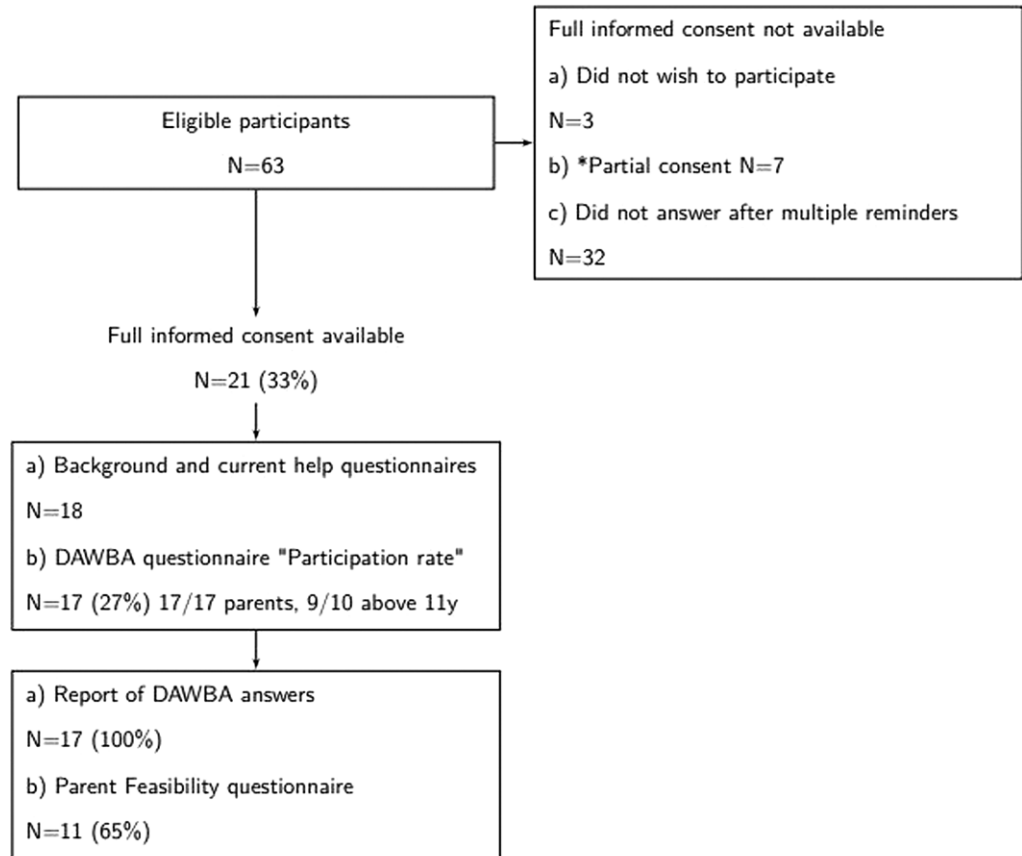


Figure 2. Flow chart of participants.

*Partial consent: one or more written consent are missing for inclusion

Feasibility

A feasibility questionnaire was sent to parents, who had completed the Development and Well-Being Assessment. The feasibility questionnaire was modified after a previous feasibility study on Development and Well-Being Assessment¹⁸ to fit this study context.

The different statements were scored on a scale from 0 to 10 (0: fully disagree, 10: fully agree). The full statements can be found in Supplementary Figure S1.

Statistical analysis

Data are presented descriptively with numeric data presented as median (range), and categorical data presented as number (%).

Psychiatric data from the DAWBA ratings will be presented as participants with any psychiatric diagnosis (ICD-10/DSM-5) (sure or unsure) and the most frequently given diagnosis will be listed.

Feasibility data will be reported as participation rate (completed DAWBAs) and parental acceptability from the feasibility questionnaire.

Study registration

The study is registered at the data protection agency of the Capital Region of Denmark (chart: P-2021-339) and at Clinicaltrials.gov (Identifier: NCT05709470) as a part of the larger “Mind the Heart” study. The Ethics Committee of the Capital Region of Denmark evaluated the project and determined that the project did not need ethical approval (chart: 20081459). The Danish Health Data

Authority provided the data needed to identify participants (chart: FSEID-00006460).

Results

Inclusion

A total of 63 children and adolescents (5–17y) with the Fontan circulation were eligible for participation in Denmark.

Written consent for participation was fully obtained for 21 participants (33%).

Of the 21 that gave full written consent, 17 completed the Development and Well-Being Assessment (participation rate 27%) (Figure 2).

Baseline information

Table 1 shows the baseline information. Participants and non-participants are generally comparable in terms of age, known syndromes, and learning difficulties. However, more participants received specialised help in school or attended special schools, while fewer had additional somatic or psychiatric disorders.

The participants are comparable to the background population in different socio-economic parameters (information from Statistics Denmark) (29% of participants’ parents had a higher education (min. of 13 years of education) compared to 37% in the background population and 41% of participants had a middle family income (500.000–1.000.000 D.kr.) compared to a middle income of 590.684 D.kr in the background population). Three-

Table 1. Baseline characteristics of participants and non-participants

	Participants (n=17)	Non-participants (N=40)*
Child age (years)		
Mean (SD)	19.9 (3.63)	-
Median (min, max)	12 (5, 17)	14 (5,17)
Child birth weight (kilogram)		
Mean (SD)	3.26 (0.48)	
Median (min, max)	3.26 (2.3, 4.1)	
Child somatic disorders besides CHD or genetic syndromes**		
No	9 (53%)	6 (15%)
Yes	8 (47%)	34 (85%)
Child medication		
No medication	0 (0%)	-
Cardiac medication	17 (100%)	-
Child genetic syndromes		
No	17 (100%)	37 (93%)
Yes	0 (0%)	3 (8%)
Child psychiatric disorders		
No	15 (88%)	29 (73%)
Yes	2 (12%)	11 (28%)
Child learning difficulties		
No	11 (65%)	31 (78%)
Yes	5 (6%)	9 (23%)
Child special schooling or special help		
No	14 (82%)	37 (93%)
Yes	3 (18%)	(8%)

*Information omission on 6 non-participants.

** Other somatic disorders: severe allergy, asthma, epilepsy, rheumatic diseases, kidney diseases, gastrointestinal-tract diseases, incl. liver diseases, severe sight and hearing disabilities, diseases that interfere with nerves or muscularfunction, and other severe diseases.

quarters of the participants had no history of parental psychiatric disorder (no background information).

Psychiatric diagnosis

Of the 17 completed Development and Well-Being Assessments, 53% ($n = 9$)(DSM-5) and 59% ($n = 10$)(ICD-10) met full diagnostic criteria for at least one psychiatric diagnosis (Table 2).

The “sure” diagnoses most frequently given were attention deficit hyperactivity disorders (3(ICD-10)/(DSM-5)) and anxiety (5(ICD-10)(DSM-5)). Three participants met diagnostic criteria for more than one diagnosis (different combinations of ICD-10/DSM-5: depression: F32.8/296.20, specific phobia: F40.2/300.29, PTSD: F43.1/309.81, oppositional conduct disorder: F91.3/313.81, separation anxiety: F93.0/309.21, Tics: F95.2/307.23).

Only 12% ($n = 2$) had a known formal psychiatric disorder (Table 1). The diagnosis formally applied matched the diagnosis given by the Development and Well-Being Assessment (attention deficit hyperactivity disorders and a diagnosis of anxiety disorder).

Among the participants who met ICD-10 diagnostic criteria, 50% had not received any psychiatric or psychological help. Of the ones that had not received any help 80% wished that they had received help.

Feasibility

The participation rate in the study was 27% (17/63).

The feasibility questionnaire was answered by 11 (11/17) (65%) parents.

Among these, 80% of the parents found the process of answering the Development and Well-Being Assessment online and reading the short report acceptable, and participants especially liked that they were able to answer the Development and Well-Being Assessment at home and online (Supplementary Figure S1).

Discussion

Twelve percent of the participating children and adolescents with the Fontan circulation in Denmark had a known psychiatric disorder. Based on psychiatric testing using the Development and Well-Being Assessment, more than half of the participants with Fontan circulation met the criteria for a psychiatric diagnosis. The most frequent diagnoses given were attention deficit hyperactivity disorders and anxiety disorders.

More than half of the participants who met the diagnostic criteria did not receive any psychiatric or psychological help and the majority of those felt there was a need for help.

Table 2. Participants with any psychiatric diagnosis based on DAWBA

Diagnostic tool	Sure psychiatric diagnosis	Unsure psychiatric diagnosis	No psychiatric diagnosis	Prevalence of psychiatric diagnosis (27–29)
DSM-5 <i>n</i> (%)	9 (53%)	2 (12%)	6 (35%)	12.7–15.5%
ICD-10 <i>n</i> (%)	10 (59%)	2 (12%)	5 (29%)	

The participation rate was 27%. Among these, 80% of parents found the process of completing the Development and Well-Being Assessment online and reading the short report acceptable, particularly appreciating the convenience of the online format.

Psychiatric disorders

Half of the participants met the criteria for a psychiatric diagnosis and the most common diagnoses were attention deficit hyperactivity disorders and anxiety disorders. This is in line with previous studies.^{7,8} The systematic review by Lau-Jensen *et al*⁷ found an increased risk of neurodevelopmental disorders (attention deficit hyperactivity disorders and autism spectrum disorder) in children and adolescents with CHD (not limited to Fontan circulation), but conflicting data on anxiety/mood disorders. In the Danish registries, the diagnoses mostly given to children and adolescents with complex CHD (not differentiated) were anxiety disorders (here including severe stress) and neurodevelopmental disorders (including attention deficit hyperactivity disorders and autism spectrum disorder).⁸

Participants and non-participants are generally comparable regarding age, known syndromes, and learning difficulties. More participants received specialised help in school or attended special schools, while more non-participants had additional somatic or psychiatric disorders. Some of those may have decided not to participate due to already being diagnosed. Despite these differences, we believe that the study represents the occurrence of psychiatric morbidity in this patient group.

When we compare the point prevalence of 53–59% of psychiatric disorders found in our participants with the known background prevalence in children and adolescents our prevalence seems high. Three meta-analyses estimated that 12.7–15.5% of children and adolescents are affected by at least one psychiatric disorder.^{27–29} Various diagnostic assessments were used in the included studies.

Although the participants in our study have regular hospital appointments (yearly or bi-yearly), we found that a large proportion who met the criteria for a psychiatric diagnosis had not been formally diagnosed.

This finding is in line with studies in both adults with CHD and in children and adolescents with other somatic disorders.^{9,10,30,31} Unrecognised and untreated mental health problems have adverse effects on later life,^{32–36} and early recognition and treatment have the potential to improve these adverse outcomes. Thus, there is a need to develop means to identify patients in need for psychiatric help.

Feasibility

Development and Well-Being Assessment has been found feasible as a screening method for psychiatric morbidities in different clinical cohorts.^{18,19} A common trait from both studies was that participants were recruited in conjunction with a clinical outpatient appointment.

This is the first study to investigate Development and Well-Being Assessment as a screening method answered online in a clinical sample of patients not recruited before nor in conjunction with a clinical appointment. Our participation rate of 27% was obtained with multiple reminders including electronic and telephone contact. As such, we find that Development and Well-Being Assessment is not ideal in this setting.

However, the participants who answered the feasibility questionnaire did find the process of answering Development and Well-Being Assessment online acceptable.

Different parts of our study procedure could have impacted our low participation rate and thereby our conclusion that Development and Well-Being Assessment is not feasible in our set-up. We believe that inviting participants through email invitations (Eboks) and not in conjunction with a clinical outpatient appointment could have decreased the willingness to participate.

Hansen *et al*³⁷ investigated Development and Well-Being Assessment in a population of Danish children and adolescents referred to psychiatric outpatient clinics. The participants were asked to participate through email (Eboks) (as in our study). They had a participation rate, similar to ours, of 30%. As children and adolescents with Fontan circulation are seen regularly at cardiac outpatient clinics, we speculate that Development and Well-Being Assessment may be feasible if patients were asked to participate in conjunction with their cardiac appointment.

Both American Heart Association and Cardiac Neurodevelopmental Outcome Collaborative (CNOC) guidelines recommend neurocognitive and psychiatric screening alongside cardiac follow-up.^{11,12}

As such a screening program is not available in Denmark yet we will continue to search for a screening tool and procedure that is feasible to use for children and adolescents with Fontan circulation. We suggest recruiting this patient group before or during clinical appointments to complete a short screening questionnaire, such as the Strengths and Difficulties Questionnaire. Patients who screen positive can then complete the Development and Well-Being Assessment online, following a protocol similar to Bennett *et al.*¹⁹ This is also more in line with the set-ups mentioned in the guidelines from CNOC that recommend different “core subsets” and more specialised measures depending on the results from the “core subsets”.¹¹ There certainly is a further need to establish and test feasible screening procedures for psychiatric disorders in this patient group.

Strengths and limitations

One strength is the use of a validated psychiatric measure. A second strength is that all diagnoses were given after a comprehensive consensus rating.

A limitation is the lack of answers from teachers. Including these would have potentially increased our diagnostic accuracy but would probably have lowered our participation rate further.

Conclusion

We found that a large proportion of children and adolescents with Fontan circulation are underdiagnosed and under-treated for psychiatric disorders. As untreated psychiatric disorders have implications on different aspects of life timely recognition and treatment are important.

This emphasises the need for a systematic screening for psychiatric morbidity in this young patient group. Further research is therefore needed to identify a feasible and reliable screening procedure with well-validated measures that can be used in daily practice.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951124026738>.

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Competing interests. Marlene B. Lauritsen is the Head of the Danish DAWBA Center. There was no payment for the use of the Development and Well-Being Assessment. The other author(s) declare none competing interests.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (The Ethics Committee of the Capital Region of Denmark) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees (data protection agency of the Capital Region of Denmark).

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